



Women
With
Disabilities
Australia
(WWDA)

Winner, National Human Rights Award 2001
Winner, National Violence Prevention Award 1999
Winner, Tasmanian Women's Safety Award 2008
Certificate of Merit, Australian Crime & Violence Prevention Awards 2008
Nominee, UNESCO Prize for Digital Empowerment of Persons with Disabilities 2020
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Nominee, UN Millennium Peace Prize for Women 2000

Senator the Hon. Linda Reynolds
Minister for the National Disability Insurance Scheme
Via Email: senator.reynolds@aph.gov.au
Via Email: Garry.Simpson@servicesaustralia.gov.au
Via Email: Michelle.Lewis@aph.gov.au

16 July 2021

Dear Minister Reynolds,

I write to you as the CEO of Women With Disabilities Australia (WWDA), as a follow up from the National Disability Insurance Scheme (NDIS) CEOs Reform Workshop held on 18 June 2021, where attendees were asked to, amongst other things, provide feedback on, *'Eight Priority Areas for Access and Planning Improvements.'*

As you would be aware, WWDA is the only national Organisation of People with Disabilities (OPD)¹ specifically for women, girls, feminine identifying and non-binary people with disability in Australia. WWDA is managed and run by women, feminine identifying and non-binary people with disability and represents more than two million disabled women and girls in Australia. WWDA has affiliate organisations and networks of women with disability in most States and Territories of Australia and is recognised domestically and internationally for our leadership in advancing the rights and freedoms of women and girls with disability.

While we appreciate and thank you and the NDIA for the opportunity to provide feedback on these 8 priority areas during the workshop; we do not consider the process was adequate to effectively communicate the views and needs of our members. Unfortunately, only 30 minutes of the Workshop was allocated to discussion of the 8 areas. Therefore, in order to complement some of the information we provided at the June workshop, we have compiled some additional feedback on the 'Eight Priority Areas' in this letter.

In addition to our extensive research on the experiences of women and girls with disability, this letter draws from anecdotal evidence from hundreds of our members, who have raised concerns about the proposed reforms to the NDIS; including, but not limited to, the introduction of independent functional assessments.

Whilst the NDIS, framed by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) - and five other human rights treaties to which Australia is a party - aims to give more 'choice and control' to people with disability; WWDA members have expressed their fears and concerns that the proposed reforms are removing control from participants about their assessment processes.

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In addition, WWDA is concerned that, if not designed and implemented correctly, the proposed reforms to the NDIS could further exacerbate the gender gap in NDIS participation rates – where, across all jurisdictions, the percentage of female participants remains at less than 37%, with some jurisdictions having even lower figures. This situation has remained unchanged since the Scheme began.²

Across the disability sector in Australia, concerns have been raised about the ability of standardised assessments conducted by an unknown professional to accurately assess an individual's 'functional capacity' and support needs. As part of the introduction of standardised assessments, the National Disability Insurance Agency (NDIA) has selected 6 assessment tools through research and testing coined the 'Assessment Toolkit'.³ As part of the assessments, the NDIA has stated that participants will be assessed according to whether they meet the 'normal functional abilities' for their age using one or multiple of these assessment tools.⁴ However, while these tools have been referred to as being adaptable to different impairment types, concern has been raised about whether they can account for fluctuating experiences, as well as differences based on other factors such as race, gender, culture, location or history of trauma.

Priority Area 1: Exemptions and alternatives to the process where required

WWDA acknowledges that concerns about the safety of individuals with a history of trauma have been briefly addressed in the NDIS 'Access and Eligibility Consultation Paper' in section 3.7 'Exemptions,' where it states: *'The delegate may decide that an applicant does not need to complete an assessment where there is a risk to safety or an assessment is deemed inaccessible or invalid.'*⁵ However, WWDA remains concerned that it is not the individual being assessed who will be empowered to make these decisions. This is particularly problematic for women with disability, many of whom have already been denied agency by guardians, family members and professionals.

In addition, there has been a considerable lack of clarity around whether the individual allied health practitioners appointed as assessors will be matched to the cultural and safety needs of disabled people, which is particularly concerning for women and girls with disability.

Across Australia, it is well known that women and girls with disability experience significantly higher rates of violence than men with disability or people without disability and are particularly susceptible to specific forms of violence, including violence and abuse perpetrated by carers, support people, healthcare practitioners and government personnel. This violence takes place not only in the home, but in a variety of institutions, including group homes, hospitals, day care settings, respite centres, boarding houses, hostels, aged care facilities, prisons, and more. Many of our members have lifetime histories of violence, including sexual violence. Many women with disability (particularly those living in group homes and other closed settings) have experienced lawful forms of violence

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such as forced sterilisation, forced contraception, menstrual suppression, forced and coerced abortion, chemical restraint and other forms of restrictive practices. For these reasons, it can be extremely traumatic and unsafe for women with disability to communicate openly with professionals with whom they do not already have long-standing, trusted relationships. For some women with disability, mandated independent assessments, conducted by a 'stranger' run the very real risk of retraumatising the individual, and causing, (or exacerbating) other impairments (such as Post Traumatic Stress Disorder; Anxiety related conditions, and so on).

For WWDA, it stands without question that the NDIA independent assessment process must be flexible, adaptable and enable exemptions to individuals who have a history of trauma. Additionally, WWDA urges the NDIA to consider alternative methods of assessment for both Aboriginal and Torres Strait Islander communities, and culturally and linguistically diverse communities, who have historically suffered mistreatment and misunderstanding from professionals.

Priority Area 2: Choice of assessor and how appointments are booked

For many people with disability, access to the NDIS has only been obtained with the support of information and reports from long-standing relationships with trusted practitioners, friends and advocates. For women with disability who have a history of violence, abuse, lack of agency, denial of legal capacity, along with misunderstanding from carers, support workers and professionals - these relationships are essential. The value and importance of natural supports and independent advocacy in this context, cannot be over-stated.

As outlined earlier, it is well known that women and girls with disability in Australia experience significantly higher rates of violence than men with disability or people without disability and are particularly susceptible to specific forms of violence, including violence and abuse perpetrated by carers, support people, healthcare practitioners and government personnel. WWDA reiterates our view (based on our experience and expertise) that there is significant risk of trauma inherent in the process of requiring women with disability to undergo an assessment by someone unknown to them.

In order to mitigate these risks, many disability advocates and gender equality experts have articulated that all assessors must be trained in practices that adhere to the (currently in progress) national trauma-informed disability practice guidelines; and that people with disability must, at a minimum, be consulted in the process of booking their assessment, including in relation to the gender and cultural background of their assessor.

For women with intellectual, cognitive and psychosocial disability, as well as Aboriginal and Torres Strait Islander women with disability, the situation is even more complex. For these cohorts,

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evidence suggests that there is a specific risk of trauma associated with being subject to an assessment with a government appointed assessor. Many of these individuals have had negative experiences with government legal and justice systems, including histories of child-removals and incarceration.⁶ For these women, it must be considered that removing the right to choose their own assessors could result in complete disengagement with the NDIS – which will only further exacerbate the recognised current inequities in access to the Scheme.

Priority Area 3: Conduct and experience of the assessor

In addition to being trained in trauma informed practices, it is essential that assessors are qualified in an area that equips them with, at the very least, a basic professional understanding of the impairments of the participant and what form of assessment will be best suited to their requirements. Among other matters, WWDA holds concern about the lack of information that has been provided by the NDIA around accreditation requirements of assessors, despite the fact that the Tune Review, which underpinned much of the proposed reform process, recommended that:

“NDIA-approved providers be subject to uniform accreditation requirements that are designed and implemented jointly by the NDIA and appropriate disability representative organisations.”⁷

Since the NDIA released its ‘Assessment Toolkit’ for assessors, and more recently, announced its decision to base funding on ‘400 personas’ of individuals, WWDA has raised serious concerns over the efficacy of standardised assessment tools to account for diverse experiences of disability, including disabled women and girls and non-binary people with disability. From decades of research, it is well known that many standardised assessment tools used by government and health professionals to assess disability, centre experiences of being white, of being middle-class, and of being male, at the exclusion of outlying experiences.

Additionally, several concerns have been raised across the sector about the ability of standardised assessment tools to accurately assess the diverse experiences of individuals within specific categories of disability. In the statement released by the Australian Autism Alliance for instance, it was noted that *“no single assessment tool solely meets the nuanced and individual needs of all autistic people.”⁸* In research such as Stephens and Bohanna’s investigation of acquired brain injury (ABI) in Cape York and the Northern Territory, it has been found that for Aboriginal and Torres Strait Islander people, there is *‘no reliable, culturally appropriate instruments to measure and assess the extent of one’s impairment.’⁹*

For these reasons, it is essential that assessors be equipped with at least a basic understanding of participants impairments and that participants be offered flexibility in their choice of assessment

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based on their will, preference, and circumstances. Amongst other considerations, assessments should be tailored to meet any accessibility and communication requirements, including access to interpreters, support people (including natural supports), information in different languages (including Easy Read and Easy English) and options to conduct the assessment in a desired format, such as by video conference or in person.

In addition, given that the NDIA Act is framed in a human rights model, and explicitly references 6 of the 7 international human rights treaties to which Australia is a party, WWDA is firmly of the view that any assessors must be able to demonstrate a clear understanding of the not only the *Convention on the Rights of Persons with Disabilities* (CRPD) but also the other human rights instruments that frame and underpin the NDIA Act. This would need to include a demonstrable understanding of how a human rights framework and approach is operationalised in practice, including in the assessment process.

Priority Area 4: Use of pre-existing participant information

Although it is important that assessors can access the necessary information to develop an understanding of the individual participant in a short period; it needs to be stressed that people with disability should not be put under pressure to unnecessarily repeat details that have already been provided to the NDIS or other professionals. For individuals who have experienced trauma related to their disability, or directly as a result of experiences with healthcare workers and other professionals, avoiding unnecessary repetitive story telling is particularly essential.

Additionally, where individuals have complex experiences, multiple impairments, or communication impairments (including low literacy levels), there should be options to base assessments on previous information from known professionals, as well as from the trusted natural supports of the individual.

This ability to provide prior information must be considered for people with intellectual and cognitive impairments who live in institutional and closed settings, who are often not afforded the agency, respect or support to effectively communicate their needs in one-off consultations.

While the proposed process attempts to address some of these difficulties by allowing people with disability to have an additional person, such as a support person or family member take part in the assessment; this requirement is likely to work against, not for, those who live in institutional and closed settings. Even though the right to make one's own choices is enshrined in a range of international human rights instruments, including the *International Covenant on Civil and Political Rights* to which Australia has been a party since 1980, women and girls with disability living in institutional settings have been, and continue to be, routinely denied the supports they require to make decisions about any matter that affects their lives.

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Rather, these women are often coerced into language and patterns of behaviour that are not in their 'best interests' through controlled and calculated 'reward' offerings, such as access to (or denial of) certain meals, outings, spending money, and/or spending time with friends and family. For these individuals, undergoing an assessment with an unknown practitioner may not only risk the assessor undermining their support needs; but could also create a situation where their carers, guardians or support workers have even more power and control over the circumstances and choices of the individual.

As an Organisation of Persons with Disabilities (OPD), WWDA strongly reaffirms that people with disability are the best source of expertise regarding how, when or if their disability affects them and understand that the views of family members, carers, support workers, guardians, and other professionals can often conflict with the reality of the disabled person's will, preferences and experiences.

Priority Area 5: Checks, inputs and reviews before the assessment is used for decision making

To ensure that the NDIS respects and supports the agency and autonomy of NDIS participants and does not further diminish their rights to make their own decisions, it is essential that assessment processes are both transparent to and collaborative with participants.

If and when participants provide pre-existing evidence or information about their disability, this should be reviewed and chosen by the participant and/or a representative of their choice. The same transparency should also be applied after the assessment, allowing adequate time for participants and their chosen support people to review assessment information and provide more documentation or evidence where necessary. It is critical in this context, that trusted, natural supports of the individual are provided the opportunity to provide qualitative and quantitative information to the assessment process, if the participant requests them to do so. This is vital – as service providers, treating doctors, support workers etc. – come and go – and it may transpire that the only continuity of information relating to the individual rests with their trusted natural and/or informal supports. It is crucial that information provided by 'professional experts' does not usurp or be given more 'status' than the information provided by natural and informal supports.

WWDA, along with many other disability advocates, are extremely concerned that the proposed process does not provide participants with a right to challenge or appeal the results of an assessment; nor does it offer alternatives, such as to undertake a second assessment with a different assessor,¹⁰ despite the Tune review recommending that the NDIA safeguard participants with the following protection:

“participants having the right to challenge the results of the functional capacity

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assessment, including the ability to undertake a second assessment or seek some form of arbitration if, for whatever reason, they are unsatisfied with the assessment.”¹¹

While it is understandable that some restrictions on the ability to appeal an assessment are necessary, there should be avenues to address errors where a participant receives an outcome of an assessment which sits in opposition with the views of their personal practitioners, friends, families and support people. Additionally, re-conducting an assessment must also be considered for people with intellectual and cognitive disability in cases where support people, such as guardians, disability workers or parents misuse their position to have an undue or inaccurate influence over the assessment.

Priority Area 6: Ongoing oversight, evaluation and improvement of assessment tools and systems

Due to the risk that standardised assessment processes invertedly exclude marginalised cohorts of people with disability and oversimplify the required process to understand support requirements, it is important that the NDIA work in collaboration with a diverse range of people with disability and their representative organisations to gain ongoing insight into the effectiveness of assessments.

WWDA draws attention to the fact that the ability of standardised assessment tools to meet the needs of Aboriginal and Torres Strait Islander people with disability and people from culturally diverse backgrounds will need to be thoroughly considered, evaluated and improved based on experience.

To do this effectively, WWDA recommends that the NDIA auspice and fund an independent oversight and advisory body that is made up of a representative cohort of people with disability.

Priority Area 7: How funds are managed in a plan

WWDA welcomes the opportunity for the NDIA to reform the way that funding can be used in NDIS participants' plans to make funds more flexible but holds concerns about the proposed process for making decisions about how funding will be allocated.

In the NDIS personalised budget papers released in 2021, it is stated that decisions about budgets allocated to participants will be made every five years, based on results from the individuals' assessment and how their situation matches one of 400 'participant personas' used by the NDIS for the purpose of consistency and fairness. It is stated that funding will be allocated under two broad categories of 'fixed' and 'flexible'; allowing for budgets to be more adaptive to inevitable changes in the way funding is distributed.

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Whilst changes that ensure more flexibility in fund allocations are welcome, it is concerning that there is a lack of clarity on how the 400 personas – which dictate overall budget – will address the intersectional experiences of women and other groups of disabled people who face multiple and compounding forms of discrimination.

As the purpose of the NDIS is to give effect to the rights of people with disabilities under the CRPD - such as the right to access supports required to participate in social, economic and cultural life to the same extent as non-disabled people - it is essential that decisions around funding allocations consider the unique and intersectional experiences of people with disability from multiple marginalised cohorts. Namely, it needs to be considered that the supports needed by an Anglo-Saxon male with one disability, will not be the same as those needed for an individual with the same disability who is a woman, is culturally and linguistically diverse, and/or is Aboriginal.

WWDA recommends that the process for allocating funding be reconsidered and adapted to reflect the diverse and intersectional experiences of people with disability, and to meet Australia's human rights obligations to provide special measures to support the rights of marginalised cohorts of people with disability,¹² such as Aboriginal people with disability, culturally and linguistically diverse people with disability and women and girls.

Priority Area 8: Plan adjustments in unique circumstances

While the proposal to move to funding allocations of five-year periods is a welcome measure that will reduce the number of unnecessary plan reviews for participants with life-long disabilities, it is important that there is room to consider the changing and fluctuating nature of disability.

For many people with disability, there is a high risk of experiencing flare ups of pain, chronic illness, or psychosocial disability, which greatly increases their support needs for short and sometimes, long periods.

In these circumstances, it is important that participants have access to clear and accessible processes that allow them to apply for plan or funding adjustments to meet their changing requirements. This is important in situations where disability or illness is exacerbated; as well as in circumstances of crisis, such as in response to natural disasters, COVID-19 lockdowns or family violence.

Thank you again for the opportunity to provide feedback on the proposed reforms to the NDIS. In addition to the recommendations in this letter, we would like to conclude by re-iterating our long-standing recommendation to the NDIA that the Agency act to develop an NDIS Gender Strategy, in consultation with women with disability and their representative organisations.

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Our organisation looks forward to continuing to collaborate with you and the NDIA.

Yours sincerely

Carolyn Frohmader
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¹ OPDs are organisations made up and governed by people with disability for people with disability. Women With Disabilities Australia is an OPD.

² National Disability Insurance Scheme (2019) [Analysis of Participants by Gender](#), National Disability Insurance Agency (NDIA). See also: National Disability Insurance Scheme Launch Transition Agency, 2020, [Analysis of participants by gender](#).

³ National Disability Insurance Scheme (2020) [The Independent Assessment Toolkit](#) National Disability Insurance Agency (NDIA).

⁴ Ibid, p.4

⁵ National Disability Insurance Scheme (2020) [Access and Eligibility Policy with Independent Assessments](#) National Disability Insurance Agency (NDIA), p. 20-21.

⁶ Australian Women Against Violence Alliance (AWAVA) (2020) [Submission to the House Standing Committee on Social Policy and Legal Affairs in response to the Inquiry into family, domestic and sexual violence.](#)

⁷ Tune, D (2019) [Review of the National Disability Insurance Scheme Act 2013: Removing Red Tape and Implementing the NDIS Participant Service Grantee](#), Department of Social Services, Australian Government, p. 66

⁸ Australian Autism Alliance (2020) [Statement on the proposed introduction of mandatory NDIA determined assessments in the NDIS.](#)

⁹ Stephens, A & Bohanna, I (2013) [Why Indigenous Australians need a properly funded NDIS.](#) The Conversation. See also at:

https://www.braininjuryaustralia.org.au/wp-content/uploads/PDF_Project_Report_9Jul13_FINALx.pdf

¹⁰ 3.11 of the NDIS Consultation paper: [Access and Eligibility Policy with Independent Assessments](#) states "Disagreeing with the results of an otherwise sound and robust independent assessment is not sufficient for the NDIA to fund another assessment. Applicants can only seek a second assessment where the assessment was not consistent with the independent assessment."

¹¹ Tune, D (2019) [Review of the National Disability Insurance Scheme Act 2013: Removing Red Tape and Implementing the NDIS Participant Service Grantee](#), Department of Social Services, Australian Government, p. 66

¹² e.g. The Committee on the Rights of Persons with Disabilities (2016) General comment No. 3. Article 6: Women and girls with disabilities. UN Doc. No. CRPD/C/GC/3 prioritises women and girls with disability as a group warranting specific attention and additional measures.

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